THE NEWBORN SCREENING SAVES LIVES REAUTHORIZATION ACT

Senators Hagan (D-NC) and Hatch (R-UT)

About Newborn Screening

Newborn screening is the practice of testing every newborn for certain genetic, metabolic, hormonal, and functional conditions that are not otherwise apparent at birth. Screening detects conditions in newborns that, if left untreated, can cause disabilities, development delays, illnesses, or even death. If diagnosed early, many of these disorders can be successfully managed.

Under every state newborn screening program, health care providers collect blood specimens at the time of birth and send the specimens to state public health laboratories for screening. Each state determines which conditions to screen for based on recommendations from the federal Secretary of Health and Human Services. If an infant tests positive for a condition, then the infant's family and doctors are rapidly notified for follow-up testing and treatment. The system is state-based and involves education, screening, diagnosis, follow-up, treatment, monitoring, and evaluation.

Newborn screening reaches each of the more than 4 million babies born in the U.S. every year. Approximately 1 in every 300 newborns has a condition that can be detected through screening. Each year, more than 12,000 babies are diagnosed with a condition detectable by newborn screening.

About the Federal Programs that Support State-based Newborn Screening

Before 2008, the number and quality of newborn screening tests varied greatly from state to state. In 2007, only 10 states and District of Columbia required infants to be screened for al recommended disorders.

In 2008, Congress passed the Newborn Screening Saves Lives Act, which established national newborn screening guidelines and helped facilitate comprehensive newborn screening in every state. Today, 44 states and the District require screening of at least 29 of the 31 treatable core conditions.

About *The Newborn Screening Saves Lives Reauthorization Act of 2013*

- Reauthorizes the HRSA grants to states to expand and improve their screening programs, educate parents and health care providers, and improve follow-up care for infants with a condition detected through newborn screening.
- Reauthorizes the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, which provides states with a Recommended Uniform Screening Panel to help ensure every infant is screened for conditions which have a known treatment.
- Establishes timelines for the Advisory Committee to review new conditions for the Recommended Uniform Screening Panel.
- Reauthorizes HRSA's Clearinghouse for Newborn Screening Information and the National Newborn Screening and Genetic Resource Center.
- Reauthorizes the CDC Newborn Screening Quality Assurance Program, the only comprehensive program in the world devoted to ensuring the accuracy of newborn tests.
- Reauthorizes the NIH Hunter Kelly Newborn Screening program, which funds research aimed at identifying new treatments for conditions that can be detected through newborn screening and developing new screening technologies.